



Indiana State Department of Health

Annual Legislative Report of the Indiana Birth Defects and Problems Registry 2018

The Indiana Birth Defects and Problems Registry (IBDPR) is a population-based surveillance system established in 1986 to monitor prevalence rates for conditions affecting fetal, infant, and child health. The goal of surveillance through the IBDPR is to develop public health initiatives for increased awareness, community education, prevention, and decreased infant mortality. Nationally, it is estimated that about one in every 33 babies is born with a birth defect each year, and birth defects remain a leading cause of infant mortality. Approximately 22 percent of Indiana infant deaths were due to birth defects in 2016.

This report covers identified cases from January 2015 through December 2017, including 47 structural birth defects for ages 0 – 3 years, fetal alcohol spectrum disorder through age 5, and pervasive developmental disorders for all ages. **Confirmed or Probable** occurrences for each were as follows:

- Structural birth defects: 6,739
- Fetal Alcohol Spectrum Disorder: 61
- Pervasive Developmental Disorders: 47

Cardiovascular, genitourinary, and musculoskeletal defects are the most **common structural birth defects** across the U.S. as well as in Indiana. Of the 6,739 structural birth defects for the reporting period:

- 3,727 were cardiovascular,
- 949 were genitourinary, and
- 784 were musculoskeletal.

Current Initiatives

The IBDPR program is participating in addressing the opioid epidemic through partnership with the Indiana Perinatal Quality Improvement Collaborative (IPQIC) to provide case reviews and follow-up for infants exposed to opioids during pregnancy. This includes utilizing standards of care established by IPQIC to ensure exposed infants have been identified and connected with appropriate healthcare resources to promote healthy growth and development.

Additionally, the IBDPR team is partnering with the Division of Fatality Review and Prevention on a Sudden Unexplained Infant Death and Sudden Death in the Young (SUID and SDY, respectively) grant project to further understand genetic causes of death, establish genetic screening as a standard death review practice, and inform programmatic direction for mortality prevention.

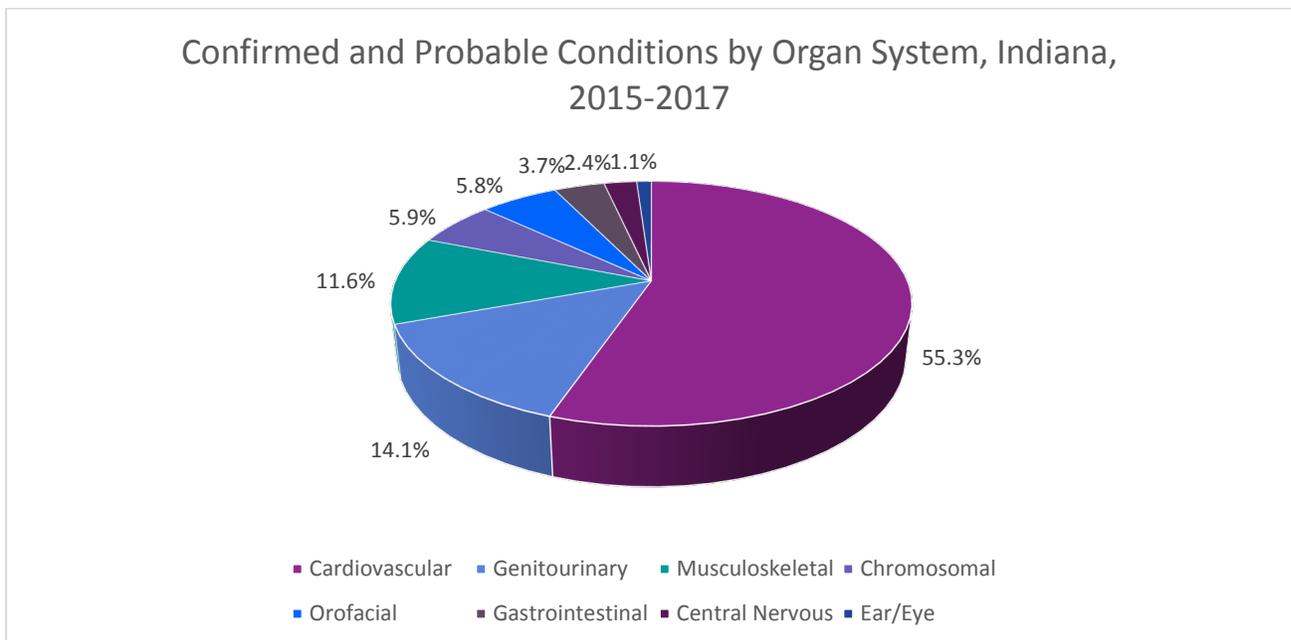
Data System Needs

The IBDPR team, along with the remainder of the Maternal and Child Health Division, is procuring a vendor for data system consultation and rebuild in order to be better able to perform population health surveillance, make referrals to services, and exchange information. This will allow for the adoption of progressive data standards that use a mixture of diagnosis codes, procedural codes, and research codes, improving the quality of reported data.

Indiana Birth Defect Rates, 2015-2017

The IBDPR monitors 47 structural birth defects categorized into eight organ systems along with fetal alcohol spectrum disorder and pervasive developmental disorders. The eight organ systems include: central nervous system, eye and ear, orofacial, cardiovascular, gastrointestinal, genitourinary, musculoskeletal, and chromosomal. Between January 2015 and December 2017, there were 6,739 confirmed or probable structural birth defects, 61 fetal alcohol spectrum disorders, and 47 pervasive developmental disorders. These occurrences indicate a prevalence rate of 274.61 per 10,000 live births for the 47 structural defects in Indiana for years 2015-2017. Of the 6,739 birth defects, 3,727 were cardiovascular, 949 were genitourinary, and 784 were musculoskeletal. Atrial septal defect had the highest number of cases, with 1,965, followed by ventricular septal defect at 1,000, and hypospadias with 786. The figure below depicts the percentage of birth defects by category.

Figure 1. Birth Defects by Category, Indiana, 2015-2017



Use of Indiana Birth Defects and Problems Registry (IBDPR) Data

The Centers for Disease Control and Prevention (CDC) collaborates with the National Birth Defects Prevention Network (NBDPN) to report prevalence rates of 47 birth defects annually. Data for the annual report is collected from each participating state and published as the “Congenital Malformations Surveillance Report: A Report from the National Birth Defects Prevention Network” in the journal *Birth Defects Research*. Data is collected for a five-year period, with years 2011 through 2015 collected this year. The IBDPR submitted data for this annual report. The annual report was the only external request for birth defect data during the past year.

Internally, data from the IBDPR is used to detect statewide trends in birth defects and emerging outbreaks impacting mothers and babies, such as Zika. The ISDH uses the information collected to identify



epidemiological factors associated with birth defects; to prepare for the next emerging threat to mothers and babies; to address community concerns about the environmental effects on adverse birth outcomes; to evaluate education, screening, and prevention programs; and to establish efficient referral systems that provide special services for the children with birth defects and their families.

Proposals for Prevention of Birth Defects and Problems in Indiana

Birth defects and birth problems occur for various reasons, including inherited genetic conditions, new (or de novo) genetic mutations, perinatal exposure to infectious disease, toxic chemicals and drugs, limited nutrients available to the developing fetus, and poor health behaviors exhibited by the mother both before and during pregnancy. While not all birth defects and problems can be prevented, the ISDH is committed to promoting upstream efforts for prevention, therefore, reducing infant morbidity and mortality.

In response to the opioid epidemic, the Indiana Perinatal Quality Improvement Collaborative (IPQIC), an advisory board to the ISDH, recommended adding the codes for neonatal abstinence syndrome (NAS) and perinatal substance use as reportable conditions to the IBDPR. The additional four (4) codes for identifying substance exposure in newborns were decided upon by IPQIC and shared with Indiana birthing hospitals in July of 2017. These codes included P04.4, P04.41, P04.49, and P96.1 in an effort to identify both exposure to substances as well as actual diagnosis of neonatal abstinence syndrome. The addition of surveying these conditions was well received by the birthing hospitals. Monitoring these conditions through the IBDPR allows for statewide data, reporting, and education. Efforts to prevent perinatal substance use, therefore reducing the risk of NAS and long-term outcomes, can be targeted at the populations most affected. Future objectives of this initiative include follow-up of identified cases to ensure connection to appropriate healthcare resources based upon established standards of care.

The Genomics and Newborn Screening team provided birthing facility outreach this year to increase awareness of the IBDPR and the impact birth defects play in infant mortality and morbidity. Every birthing facility was given a toolkit with resources about birth defects and the IBDPR. An IBDPR brochure was created for parents and community partners. The brochure provides the community basic education about birth defects, the importance of the IBDPR program, and the role IBDPR plays in infant mortality. Additionally, the Genomics and Newborn Screening team plans to provide primary care provider education to increase awareness of the IBDPR and the provider requirement to report, as well as, general knowledge of birth defects and their impact on infant morbidity and mortality in 2019.

Additionally, the IBDPR team partnered with the Division of Fatality Review and Prevention to further understand genetic causes of death for Sudden Unexplained Infant Death (SUID) and Sudden Death in the Young (SDY). This partnership will allow for stronger understanding and increased awareness of the chromosomal anomalies resulting in the high infant mortality rate in Indiana, as well as improve standards of death review to include genetic screening and help to direct programmatic practices for upstream mortality prevention methods.

Indiana County Data for Years 2015-2017

Currently, IB DPR collects data on 49 conditions, 47 of which are structural anomalies designated nationally by the CDC. Indiana also collects data on pervasive developmental disorders and fetal alcohol spectrum disorders. The prevalence rate for the 49 targeted conditions in Indiana for the three-year time period was 279.01 per 10,000 live births. Counties with fewer than 20 cases do not have stable rates and should not be compared. Counties near Cincinnati, Ohio; Louisville, Kentucky; and Chicago, Illinois, may be underreported due to families seeking care in large healthcare facilities across state lines (ex. Cincinnati Children’s Hospital, Norton Children’s Hospital, and Lurie Children’s Hospital, respectively). The counties with the five highest rates were Warren (572.69 per 10,000), Huntington (439.56 per 10,000 live births), Randolph (405.09 per 10,000 live births), Delaware (404.71 per 10,000 live births), and Sullivan (403.88 per 10,000 live births). Gibson, Jackson, Clark, LaGrange, and Dubois counties had the lowest rates, with 166.94, 177.38, 177.40, 182.82, and 189.24 per 10,000 live births, respectively. The map below shows a comparison between county rates and the state rate for birth defects, fetal alcohol syndrome, and pervasive developmental disorders. Counties in green have a lower rate than the state, counties in red have a higher rate, and counties in yellow have an unstable rate and should not be compared. Table 8 below shows the rate of birth defects, fetal alcohol syndrome, and pervasive developmental disorders per county in Indiana. Counties with fewer than five (5) cases have been suppressed for confidentiality.

Figure 2. Comparison of County to State Rate of Birth Defects, Fetal Alcohol Syndrome, and Pervasive Developmental Disorder

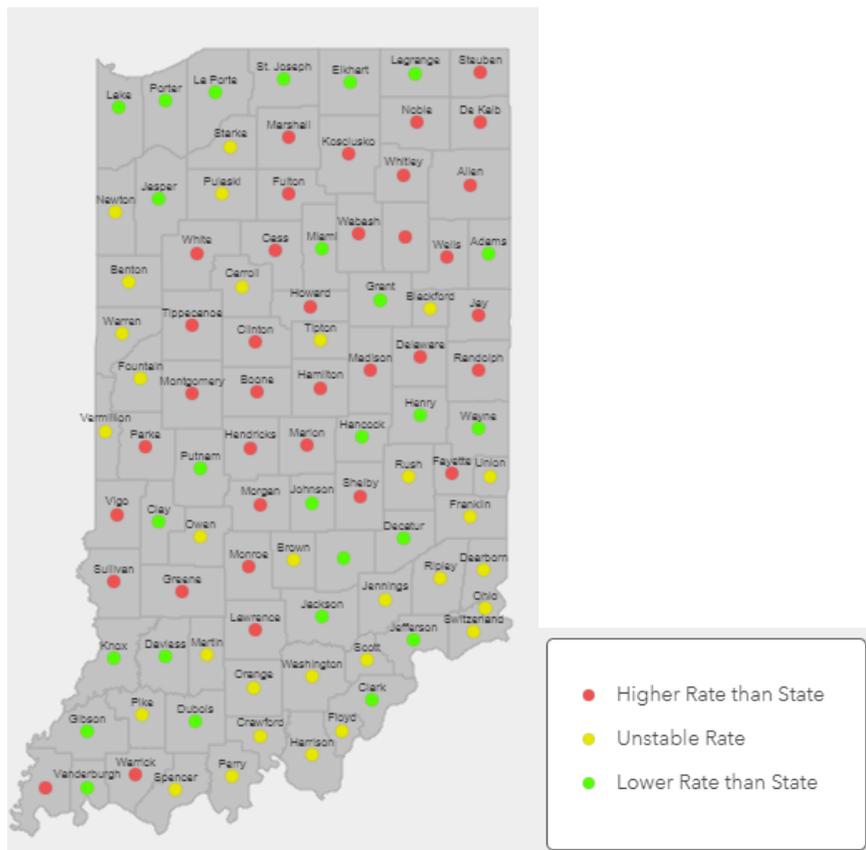


Table 1. Birth Defect Rates by County, Indiana, 2015-2017

County	Confirmed or Probable Cases	Prevalence rate per 10,000 live births
Adams	43	212.77
Allen	570	366.25
Bartholomew	62	192.55
Benton	7	214.72†
Blackford	15	398.94†
Boone	87	368.96
Brown	11	314.29†
Carroll	14	215.38†
Cass	52	363.64
Clark	62	177.40
Clay	25	257.20
Clinton	48	360.36
Crawford	*	63.29†
Daviess	37	230.10
Dearborn	No data	No data
Decatur	27	254.96
De Kalb	51	326.50
Delaware	141	404.71
Dubois	32	189.24
Elkhart	215	229.41
Fayette	23	361.64
Floyd	23	361.64
Fountain	14	270.27†
Franklin	*	96.15†
Fulton	24	333.33
Gibson	20	166.94
Grant	43	193.96
Greene	37	365.97
Hamilton	357	311.44
Hancock	57	232.08
Harrison	6	51.11†
Hendricks	149	285.17
Henry	36	258.62
Howard	94	319.95
Huntington	56	439.56
Jackson	32	177.38
Jasper	29	257.09

County	Confirmed or Probable Cases	Prevalence rate per 10,000 live births
Jay	30	355.87
Jefferson	24	225.35
Jennings	18	186.72†
Johnson	130	234.53
Knox	32	248.06
Kosciusko	119	383.38
Lagrange	40	182.82
Lake	410	253.82
La Porte	85	219.35
Lawrence	43	292.92
Madison	163	369.95
Marion	1265	286.70
Marshall	54	300.50
Martin	*	110.80†
Miami	29	261.97
Monroe	115	294.95
Montgomery	43	311.82
Morgan	89	372.85
Newton	10	232.56†
Noble	68	364.42
Ohio	No data	No data
Orange	9	125.87†
Owen	18	279.94†
Parke	20	315.46
Perry	16	274.44†
Pike	12	291.26†
Porter	121	243.41
Posey	23	288.22
Pulaski	15	383.63†
Putnam	28	250.45
Randolph	35	405.09
Ripley	11	122.36†
Rush	11	191.97†
St. Joseph	276	263.28
Scott	8	101.27†
Shelby	49	331.08
Spencer	*	54.45†
Starke	16	198.76†
Steuben	44	379.31

County	Confirmed or Probable Cases	Prevalence rate per 10,000 live births
Switzerland	*	92.59†
Tippecanoe	269	387.38
Tipton	13	288.89†
Union	*	119.05†
Vanderburgh	168	255.59
Vermillion	8	167.01†
Vigo	127	336.33
Wabash	29	287.41
Warren	13	572.69†
Warrick	57	293.06
Washington	11	123.60†
Wayne	47	214.61
Wells	33	317.61
White	28	311.46
Whitley	45	371.59
Indiana	6846	278.97
Notes:		
* indicates fewer than 5 cases and are suppressed for confidentiality		
† Numerator less than 20, the rate is unstable. We do not recommend comparing unstable rates		